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Autism in the Somali Population: Exploring the inter-relatedness of the Somali immigrant and refugee experience navigating Speech-Language Pathology resources

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Introduction

Approximately 15,711 Somali immigrants resettled in Minnesota in 2016 (Rush, 2016). According to the Rochester Post Bulletin, the Med City ranks fourth place in number of Somali immigrants, 333, behind Minneapolis at 3,450, St. Cloud at 1,393, and St. Paul at 960 (Post Bulletin, 2017). In a study conducted by the Minnesota Department of Health in 2008, the most common services needed by Somali families was first housing, followed by speech therapy second (Minnesota Department of Health, 2014). In a study conducted by the Minnesota Department of Health in 2008, the most common family or individual challenges associated with late identification of autism included lack of knowledge about autism, lack of knowledge about resources, and stigma (Minnesota Department of Health, 2014). There are currently no specific guidelines on how to best provide language assessment and intervention services for a refugee or immigrant population who is speaking a language for which there is no developmental information. In addition, there is no current research to determine what the language skills demonstrated by Somali refugee/immigrant children are a result of. Some of the leading influences include: deprivations in refugee camp, normal language interference when learning a second language, language acquisition, culture shock, mental health issues, familial conflict, poor nutrition and maternal health, differing views on health beliefs and practices or communication disorders such as Autism, or a combination of several of these.

This literature review brings together information from 9 impact areas to create a better understanding of overlapping impacts on Somalian children. For the purposes of this study, the term “children” refers to individuals under the age of 18 years old. The clinical implications of these findings help to build an inclusive assessment tool that documents all the factors that need to be taken into consideration in determining the need for language intervention in Somali refugee/immigrant school aged children. The RIOT, also known as review records, interview all involved parties, observe the child in several settings, and test the child, was created by Dr. Li-Rong Lilly Cheng. The RIOT is used to structure these findings. Dr. Cheng is a world-renowned Speech Language Pathologist whose area of expertise is multicultural/multilingual language assessment and intervention (Cheng, L.L., 2007). This research focuses on the linguistic and health impacts of learning a second language. The purpose of this research is to analyze the Somali population using the 9 impact areas discussed to explore the inter-relatedness of the Somali refugee and immigrant experience pertaining to navigating Speech-Language Pathology resources and therapy.

RIOT Model Significance

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The rise in Somali immigrants to the United States makes the need for accessible, proactive speech therapy services a high priority. Minnesota makes up 2 percent of the nation's population; however, Minnesota has 13 percent of the nation's refugees (Post Bulletin, 2017). Autism spectrum disorder (ASD) is among the fastest growing developmental disability diagnosis in the United States (Hewitt, A., Hall-Lande, J., Hamre, K., Esler, A. N., Punyko, J., Reichle, J., & Gulaid, A. A., 2016). There are numerous pieces of literature that analyze specifically the impact on children in this particular population. A report from Swedish neurologists, published in 2008, states the prevalence of autism spectrum disorders in Somali children aged 7 to 17 years is almost four times higher than in non-Somali children (Barnevik-Olsson, Gillberg, & Fernell, 2008).

The first area of impact on language skills demonstrated by Somali refugee/ immigrant children is the result of deprivations during their time in refugee camps. It is important to analyze the historical context of this population and understand their past experiences. The United States has resettled many groups of Somali refugees who have experienced civil war and a lack of formal government (Jaranson, J. M., Butcher, J., Halcon, L., Johnson, D. R., Robertson, C., Savik, K., & Westermeyer, J., 2004). Many of these individuals are forced into misplacement, often fleeing their own country for fear of losing their life. The civil war in Somalia resulted in massive resettlement of Somali refugees (Pavlish, Noor, & Brandt, 2010). The largest group of Somali refugees in the United States currently resides in Minnesota (Pavlish, Noor, & Brandt, 2010). The findings from one study suggests that many young Somali immigrants to the United States experience life problems associated with war trauma and torture (Halcón, L. L., Robertson, C. L., Savik, K., Johnson, D. R., Spring, M. A., Butcher, J. N., & Jaranson, J. M., 2004). Of the 338 participants, aged 18 to 25 years old, many of them had difficulty identifying coping strategies (Halcón et al., 2004). In this literature, this is a recurring theme, the lack of age-appropriate strategies to promote the health of refugee youth to facilitate their successful adaptation to adult life in the United States (Halcón et al., 2004).

The second area of impact on language skills demonstrated by Somali refugee/ immigrant children is the result of normal language interference when learning a second language. Often, communication is derived from the point of view of "normal", that is whatever the population of that language define as normal (Ranta, 2009). Between two languages there are differences and similarities that sometimes are spoken incorrectly, but unintentionally. To avoid being incorrect, refugees and immigrants will often experience what is considered normal language interference as they adapt to new customs and practice. They will transfer phrases or portions of one language to the other only to later understand the error. The effect of one language on the performance in another, or a negative, cross-linguistic interference can have a deleterious effect on language performance (Kohnert, 2010). Although it can take time to produce words, find

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confidence in practice, and eventually grow to a level of fluency, it can take much longer for Somali immigrants and refugees who are not supported adequately.

The third area of impact on language skills demonstrated by Somali refugee/ immigrant children is the result of second language acquisition. Somali immigrants and refugees overcome an enormous wave of cultural differences when adapting to the United States. In addition to obstacles such as illiteracy, lack of English skills, immigrant status, lack of formal education, and no modern-economy job skills, the Somali will also face the obstacle of discrimination inherent in American society (Van Lehman & Eno, 2002). For these reasons, it is suggested that American resettlement professionals devote sufficient resources to help the Somali overcome the immense language challenges they will face in the United States.

The fourth area of impact on language skills demonstrated by Somali refugee/ immigrant children is the result of culture shock. Socially, there are bigger picture issues happening in the United States that are making resettlement more difficult. A study conducted by BMC public health distinguished multiple social constituents that lead to poorer health outcomes for the Somali Population. Their overall qualitative and quantitative results suggested that challenges to masculinity, thwarted aspirations and devalued refugee identity (Warfa, N., Curtis, S., Watters, C., Carswell, K., Ingleby, D., & Bhui, K., 2012). These negative stigmas and voices manifest themselves in staggering numbers. According to the study, unemployment, legal uncertainties and longer duration of stay in the host country account for poor psychological well-being and psychiatric disorders among this group (Warfa et al., 2012).

The fifth area of impact on language skills demonstrated by Somali refugee/ immigrant children is the result of mental health issues. One study looked at 600 Somalian refugees who experienced Post-Traumatic Stress Disorder (PTSD). Of those studied, most Somali female patients showed predominantly depressive and PTSD symptomatology (Kroll, Yusuf, & Fujiwara, 2011). The identity of immigrant or refugee carries a lot of weight into various aspects of their resettlement in Minnesota. According to the Minnesota Department of Human Services, difficulties working within the patriarchal family structure, limited community resources, poor compliance, and financial issues ranked among the highest concern (Scuglik, D. L., Alarcón, R. D., Lapeyre III, A. C., Williams, M. D., & Logan, K. M., 2007).

Children with symptoms of PTSD reported more traumatic events (Halcón et al., 2004). In fact, trauma history was strongly associated with physical, psychological, and social problems (Halcón et al., 2004). Currently, the most frequent strategies to combat the sadness they experienced included praying, 55.3%, sleeping, 39.9%, reading, 32.3%, and talking to friends, 27.8%. In the same study, 61% of women compared to 24% of males reported feeling alone (Halcón et al., 2004).

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The sixth area of impact on language skills demonstrated by Somali refugee/ immigrant children is the result of familial conflict. An example of the barriers that were mentioned in one study included problems working with patients from 'warring clan factions' and patients' fears of being labeled 'crazy,' by their family members (Scuglik et. al, 2007). Within the Somali community, there are many difficulties viewing illness within an emotional framework and the need to address mental health from a physical framework through a focus on somatic symptoms (Scuglik et. al, 2007). To understand in a deeper context a lot of personal decisions stem from cultural practices in the Somali community. For example, Somalis rarely acknowledge psychiatric problems and common traditional treatments have become ineffective in the new context (Scuglik et. al, 2007). The Somali community still practices female genital mutilation and diagnosis autism as belonging to the larger umbrella diagnosis of schizophrenia (Scuglik et. al, 2007).

The seventh area of impact on language skills demonstrated by Somali refugee/ immigrant children is the result of poor nutrition and maternal health. One of the larger concerns facing this population are factors that influence Somali women's health experiences (Pavlish, Noor, & Brandt, 2010). One of the more polarizing topics for this population is female circumcision, which is regularly practiced in their culture. One study examined 57 Somali women and interviewed 11 key informants including Somali healthcare professionals (Pavlish, Noor, & Brandt, 2010). The categorical findings from this study analyzed healthcare experiences (Pavlish, Noor, & Brandt, 2010). The results found that Somali women's health beliefs related closely to situational factors and contrasted sharply with the biological model that drives Western medicine (Pavlish, Noor, & Brandt, 2010).

The poor access to maternal health of Somali Immigrants and Refugees has severe consequences for their prenatal care and pregnancy outcomes. One study linked higher maternal intake of nutrients and health supplements were associated with a reduction in ASD risk (Lyall, K., Schmidt, R. J., & Hertz-Picciotto, I., 2014). This evidence was particularly strong for periconceptional folic acid supplements (Lyall, K., Schmidt, R. J., & Hertz-Picciotto, I., 2014). However, if Somali Immigrants and Refugees are not able to seek proper medical care they are not able to gain access to nutrients that have been scientifically linked to reducing ASD links. "A number of studies have demonstrated significant increases in ASD risk with estimated exposure to air pollution during the prenatal period, particularly for heavy metals and particulate matter" which many low-income immigrants and refugees are often housed in (Lyall, K., Schmidt, R. J., & Hertz-Picciotto, I., 2014).

Environment has an enormous impact on health. Although there is currently no single environmental factor that is able to explain the increased prevalence of autism, there are a handful of environmental risks (Dietert, R. R., Dietert, J. M., & DeWitt, J. C., 2011). "It is clear that many significant risk factors, remain to be identified" and further research is necessary

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(Dietert, R. R., Dietert, J. M., & DeWitt, J. C., 2011). This particular study found that “the most promising risk factors identified to date fall within the categories of drugs, environmental chemicals, infectious agents, dietary factors, and other physical/psychological stressors” which has been amplified throughout several studies (Dietert, R. R., Dietert, J. M., & DeWitt, J. C., 2011).

The eighth area of impact on language skills demonstrated by Somali refugee/ immigrant children is the result of differing views on health beliefs and practices. The differences in health beliefs and practices resulted in diverged expectations regarding treatment and healthcare interactions (Pavlish, Noor, & Brandt, 2010). The women in the study often recalled experiencing unmet expectations while with their provider (Pavlish, Noor, & Brandt, 2010). Somali women and their healthcare providers reported multiple frustrations which often diminished the perceived quality and confidence in their care (Pavlish, Noor, & Brandt, 2010). One study identified cultural barriers leading to six major themes in declined health for Somali women (Hill, Hunt, & Hyrkäs, 2012). These six themes included: pregnancy as a natural experience for women, value and relevance of prenatal care, lack of control and familiarity with delivery in the United States, balancing the desire to breastfeed with practical concerns and barriers, discomfort with mental health issues, and challenges in the healthcare system (Hill, Hunt, & Hyrkäs, 2012).

The eighth area of impact on language skills demonstrated by Somali refugee/ immigrant children also includes differing beliefs and practices to treat communication disorders such as Autism. While analyzing the autism rates in this population, it is important to include a socio-ecological perspective to gain larger influences on the conditions they live with and the care they receive. The cultural impact has yet to be diagnosed for the prevalence of autism spectrum disorder (ASD) is high yet remains largely unstudied.

Non-White children are less likely to be diagnosed with ASD (Mandell et al. 2009), and those who are diagnosed receive a diagnosis later than white children (Mandell et al. 2002). These disparities reflect several complex issues such as access to care, cultural appropriateness of screening and assessment, and cultural expectations of child development and disability. The ability to diagnose autism early is an enormous influence of social, emotional, and general wellbeing (Hewitt. et al., 2016). As the national rates of ASD have increased, the United States has also seen a significant and simultaneous increase in the number of children and families from culturally and linguistically diverse communities (Hewitt. et al., 2016).

In addition to the eight factors described above, the ninth involves a combination of several different sets of the first eight. It is crucial in this time where Minnesota is one of the largest areas of resettlement for the Somali population that they look with a critical eye on their system and resources. Immigrants and refugees are facing unforgiving obstacles, some of which include

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a complex health diagnosis, financial instability, and the social scrutiny of their new community. Autism rates are on the rise and it is important that the health care and education systems are adequately prepared to meet the needs of individuals who speak a different language and have different cultural practices. Minnesota, as well as the United States must strive to reflect an inclusive, welcoming atmosphere, this begins with every individual we welcome to our country.

From the aspect of the current healthcare system, there are many factors that are contributing to less than acceptable health treatment of Somali Immigrants and Refugees. According to a research study conducted by Von Kaehne (2002), discovered that one of the major factors leading to patient's distress is often “cultural or social pressures from within their community”. In many scenarios, if the patient is placed in the position to talk about their care in front of another person, “even if that person is a professional interpreter, they may feel unable to speak openly and honestly” (Von Kaehne, 2002). The study found that many non-English speakers “take great comfort from the anonymity of a telephone interpreter” since the physical presence is not necessarily there (Von Kaehne, 2002). Many Somali Immigrants and refugees must “rely on friends or family members to help them” navigate the very unfamiliar healthcare system (Von Kaehne, 2002). Although it is ideal that Somali Immigrants and Refugees would be matched “with an interpreter, health advocate, or bilingual member of staff”, it often is not the reality (Von Kaehne, 2002).

Statistical Significance

In addition to surveying the 9 impact areas of language for the Somali Immigrants and Refugees, utilizing secondary data to explore the problem, is immensely beneficial. In 2014, the Minnesota Department of Health adapted the United States Center for Disease Control database to survey Autism Spectrum Disorder in Minnesota (Minnesota Department of Health, 15 February 2014). In 2013, a Community report was created to further investigate the Minneapolis Somali Autism Spectrum Disorder Prevalence for their project (Hewitt, A., Gulaid, A., Hamre, K., Esler, A., Punkyo, J, Reichle, J., & Reiff, M., 2013). These two databases have obtained a more comprehensive statistical analysis of the prevalence of autism in Somali populations within Minnesota specifically.

The data shows that “Somali children with ASD were significantly more likely to have an intellectual disability than children with ASD in all other racial and ethnic groups” (Hewitt, A., Gulaid, A., Hamre, K., Esler, A., Punkyo, J, Reichle, J., & Reiff, M., 2013). Recently studies in Minneapolis, Minnesota have isolated that autism has a prevalence of 1 in 36 in white children and a prevalence of 1 in 32 for Somalian children living in the same area (Hewitt. et al., 2016). The national average is one child in 88 are on the autism spectrum according to the C.D.C. 's Center on Birth Defects and Developmental Disabilities. (McNeil, 2013). Despite the heightened awareness and growing concern surrounding early diagnosis, there is still not sufficient literature and research.

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Conclusions/ Recommendations

There are no studies that exist examining the Somali Immigrant and Refugee Population and their assimilation to AAC Speech Technology for Autism Spectrum Disorder. It is recommended that future research be dedicated to this and to the Minnesota population specifically.

Mental health services, maternal services, nutrition programs in schools, and family therapy can alleviate lots of the symptoms the Somalian population is experiencing. These community services can help target areas that the population is most concerned about.

Unfortunately, deprivations in refugee camp is a difficult factor to control since it often happened before they arrive in the United States. Language interference and language acquisition can be targeted through Speech Therapy Services.

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